

## **Patient-Reported Outcome Measures and Patient-Reported Experience Measures**

Healthcare continues to move towards a more patient-centred approach and with this comes the requirement for the patient to be more involved in their care. Additionally, healthcare is focusing more on quality improvement, providing better services, and improved patient outcomes. One result of this shift in how health care is delivered is the need for patient-reported measures to gain insight into the patient's perspective and experience of the care they receive. Two of these measures are patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs).

### **What are PROMs?**

PROMs are standardized measurement tools (questionnaires) administered to patients that are validated for assessing the patient's perspective on aspects of their health status, disability, and health-related quality of life<sup>1</sup>. PROMs generally assess factors such as symptoms, function, pain, physical and mental health; and also capture patient perspectives on aspects of their health status that are not typically captured by standard diagnostic tools<sup>2</sup>. PROMs are usually designed to compare health status and/or outcomes pre and post intervention and are therefore utilized to inform the clinical management of patients<sup>1</sup> and to measure clinical effectiveness and safety of an intervention from the perspective of the patient<sup>3</sup>. Because PROMs facilitate an understanding of how effective care delivery is from the patient's perspective, they are critical to determining whether healthcare services and procedures are positively impacting a patient's health status and health experiences, especially when combined with existing information on the quality and delivery of healthcare<sup>2</sup>.

PROMs may be generic or disease-specific. Generic PROMs measure a broad range of factors that can correspond to a variety of medical conditions and can be used to evaluate the cost-effectiveness of an intervention, care delivery, and quality of life<sup>4</sup>. The EuroQol Group 5-D Instrument (EQ 5-D)<sup>5</sup> is an example of a generic PROMs tool which captures quality of life measures across areas such as mobility, self-care, and pain and discomfort. Disease-specific PROMs allow for assessment of aspects of a particular condition and how these impact outcome, such as the European Organization for Research and Treatment of Cancer Quality of Life – Gastric Cancer (EORTC QLQ-STO22)<sup>6</sup>.

### **PROMs in Canada**

The Canadian Institute for Health Information (CIHI) noted that while some countries such as the United Kingdom have comprehensive PROMs programs to evaluate health services and outcomes, no coordinated program for routine administration of PROMs for use in health services management, quality improvement and performance

measurement existed on a national level across Canada. In recognition of this and the wide range of possible uses of the data that PROMs provide as well as the potential benefit of a coordinated program to collect PROMs, spurred by stakeholder interest the CIHI embarked on a PROMs program in 2015. This program aimed to provide leadership to advance standardized approaches to PROMs in Canada and to support the development of PROMs data collection standards and reporting in priority areas beginning with hip and knee replacement surgeries<sup>7</sup>. The CIHI further created a background document to provide a common understanding of PROMs including the value of PROMs and their use internationally and in Canada, and a framework for initiatives to develop PROMs<sup>8</sup>. In its review, the CIHI found that the EQ-5D, the 36-Item Short Form Health Survey (SF-36)<sup>9</sup>, and the Health Utilities Index (HUI)<sup>10</sup> (originally developed by McMaster University), were some of the generic PROMs tools being used nationally and provincially in Canada.

In 2019, the CIHI published the Patient-Reported Outcome Measures Data Collection Manual: Hip and knee Arthroplasty<sup>11</sup> as a national standard to outline guidelines and recommendations for PROMs instruments, survey collection times, and minimum data sets to be collected.

### **What are PREMs?**

PREMs are questionnaires used to measure the patient's views of their experience while they were receiving care. They focus on the process of care and how it impacted the experience of the patient<sup>1</sup>. PREMs evaluate areas such as communication and trust in staff, timeliness, and cleanliness; data that can be used to assess and monitor service delivery<sup>12</sup>. PREMs do not measure the outcome of care but rather look at the impact that that care had on the patient's experience. They report on objective patient experiences and in that way differ from patient satisfaction surveys. PREMs may be relational, identifying the patient's experience of their relationships during treatment such as whether they felt listened to; or functional, examining more practical issues, such as the facilities that were available<sup>3</sup>. An example of a relational PREMs tool is the Consultation and Relational Empathy (CARE) measure<sup>13</sup>.

### **PREMs in Canada**

Many PREMs tools are available, and similar to PROMs, the CIHI found that there were no standardized tools being used across Canada for collecting and reporting PREMs, a necessity for data comparability. In response to a request from jurisdictions, the CIHI developed the Canadian Patient Experiences Survey— Inpatient Care (CPES-IC)<sup>14</sup> in 2013, pilot tested and released it along with supporting documents (data dictionary and survey procedure manuals) in 2014. CPES-IC is non-proprietary, publicly available, and has been endorsed by Accreditation Canada. It is a standardized questionnaire that

collects data on the patient's experience following a recent stay in an acute care hospital in Canada. Following on the CPES-IC, the CIHI developed the Canadian Patient Experiences Reporting System (CPERS)<sup>15</sup> and has begun a phased approach to the public reporting of patient experience data. CIHI is working with partners to develop a standardized PREMs tool for use in long-term care (LTC) facilities. A patient experience survey is a requirement of the accreditation process for LTC organizations.

### **PROMs and PREMs in Research**

PROMs were initially developed for use in research<sup>16</sup> but their use has expanded beyond clinical research, fuelled by the recognition of their potential to transform healthcare and improve quality and safety<sup>4</sup>. They are important research tools that if utilized well, can provide standardized, comparable data on health care delivery and the effectiveness of treatment options, which when combined with other data being collected, can be utilized to improve health systems and the quality of healthcare. PROMs and PREMs can be used to measure metrics that are relevant to patients such as which treatment option is better? How will I feel after surgery? What will my quality of life be like after this procedure? Which health care facility has better patient outcomes? They are also useful for healthcare decision-makers, providing a visual of what aspects service delivery needs improvement, the best treatment options to invest in, and how to improve the quality of healthcare and thus improve the bottom-line of the organization.

## References

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